

Dear Committee Members,

I would like to thank the members of the committee for raising another bill that would allow children in need access to medicinal marijuana. I am writing as the concerned parent of a young child who suffers from uncontrolled seizures. I have a six year old daughter who lives with Dravet Syndrome. Dravet Syndrome is a very rare and severe form of epilepsy, which is remarkably resistant to traditional pharmaceuticals. It presents within the first year of a baby's life, and begins with prolonged seizures that are difficult to stop. My daughter has been intubated four times and has stopped breathing five times. She typically has absence seizures, but has had all other types (myoclonic, atonic, tonic clonic, etc). Her longest seizure was a grand mal that lasted over two hours. She nearly died from cardiac arrest. To this day, she has never had a seizure that stopped on its own. Each seizure requires emergency intervention.

Dravet Syndrome affects children in different ways, including:

- Regression in fine and gross motor skills
- Loss of cognitive skills.
- Weakened immune systems, leading to more seizures.
- Higher mortality rate due to prolonged life-threatening seizures (Every month, a minimum of one young child dies from this awful disease due to complications).

This condition is devastating. I have lost count of how many seizures my daughter has had, along with how many ambulance rides and hospitalizations she has had to endure. I can honestly say that my entire family is in constant fear for her life. It has been over 4 years since I have been able to sleep without worry.

About Ella:

- She is on three medications and two supplements which adds up to 15 pills per day (side effects include: permanent brain damage, aggressive behavior, increased or decreased appetite, loss of balance, fatigue, inability to sweat, cognitive impairment, loss of liver/kidney/pancreatic functions, etc).
- She is on a strict medical diet called the Ketogenic diet, which requires my husband and me to carefully measure all of her meals on a gram scale (side effects include: slow growth, kidney stones, loss of liver and kidney function, acidity of the blood, etc).
- She has seizures no less than once a month despite all of her medications and supplements.

The passage of Bill 5450 is necessary. The current approved pharmaceuticals are not sufficient at treating my daughter's disease. She currently has the choice between suffering through multiple uncontrollable seizures, or ingesting toxic chemicals that do not control her seizures completely. My daughter deserves access to another option, a natural treatment that has no proven negative side effects. It is necessary to study the entire cannabis plant for its efficacy in treating this illness. It has been used in children with Dravet Syndrome and other illnesses in Colorado and has been found to be successful most of the time. It has not been FDA approved but it is giving families hope. In a life where I am facing my child's mortality on a daily basis, it is necessary to find the path towards hope. I want my daughter to live a life where she can play outside, where she can eat normal food, and where I can sleep at night knowing she will be safe while she sleeps.

Please do not let fear of the unknown sway your decision. I have to live with this fear every day. At 10 months old my daughter was prescribed a medication (Keppra – Levetiracetam) that had only ever been prescribed to adults. We were told by the prescribing neurologist that although it had not been researched nor was there any literature for use in children, he believed it was worth trying. How is pediatric use of medical marijuana any different? Our children are medically fragile, not future drug dealers as some fear mongers might state.

As a parent of a child who would most definitely benefit from the use of medical marijuana, I urge you to consider passing Bill 5450. I, along with other parents of children with Dravet Syndrome and other potentially fatal conditions in Connecticut, have only the best of intentions for our little ones. Many of the children who have access to medical marijuana have been able to decrease their daily medications and/or end them completely.

Thank you all so very much for raising this bill. My daughter and the other children suffering from life-threatening conditions deserve better. They deserve more options than what have already been proven to fail. All it takes is one uncontrollable seizure for my daughter to be taken from us.

Thank you for your consideration,

Dana E. Haddox-Wright